

HUMAN SERVICES

DIVISION OF MENTAL HEALTH SERVICES

Family Support Services

Proposed Readoption with Amendments: N.J.A.C. 10:37I

Authorized By: Gwendolyn L. Harris, Commissioner,

Department of Human Services

Authority: N.J.S.A. 30:4-177.43 et seq., specifically 30:4-177.52.

Calendar Reference: See Summary below for explanation of exception to
calendar requirement.

Proposal Number: PRN 2003-275

Submit comments by September 19, 2003 to:

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Legal Liaison

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The agency proposal follows:

Summary

Pursuant to N.J.S.A. 52:14B-5.1(c), N.J.A.C. 10:37I, Family Support Services, expires on July 30, 2004. The Department of Human Services (the Department), through the Division of Mental Health Services (the Division), has reviewed these rules and has determined them to be necessary, reasonable and

proper for the purpose for which they were originally promulgated. Some amendments are necessary in order to clarify, update, and streamline regulatory language. Other amendments propose more substantive changes, as explained further herein. Therefore, the Department is proposing to readopt these rules with amendments.

As the Department has provided a 60-day comment period for this notice of proposal, this notice is excepted from the rulemaking calendar requirement, pursuant to N.J.A.C. 1:30-3.3(a)5.

The purpose of these rules is to govern the planning and delivery of family support services required by P.L. 1995, c.314 (N.J.S.A. 30:4-177.43 et seq.) and funded by the Division of Mental Health Services to families who provide care in the community for a family member with a serious mental illness. These rules assure an organized system of family support, promote the efficient and effective use of State funds by providers, and assure that quality services are delivered to families with a mentally ill member.

When families are integrally involved in the care of a family member with a serious mental illness, the families should be provided with the supports they need to sustain that family member with dignity in a community setting, within available funding limits. Family support services are a coordinated system of on-going public and private support services which are designed to maintain and enhance the quality of life of a family and improve its functioning. An important component of this system is Intensive Family Support Services comprised of a range of family driven supportive activities including, but not limited to,

psychoeducation, individual family consultations, multiple family support groups, respite, referral/service linkage and advocacy. Services shall be offered to parents, spouses, siblings and children of adults with a serious mental illness. Others who may use such services include relatives who are closely involved in and concerned about the ill family member's daily functioning, or non-relatives who are the ill member's primary caregivers.

The rules are comprised of five subchapters. N.J.A.C. 10:37I-1.1 defines the scope and authority of these rules proposed for readoption. N.J.A.C. 10:37I-1.2 details the scope of the Family Support Program. N.J.A.C. 10:37I-1.3 provides the definitions for the words and terms used in these rules. N.J.A.C. 10:37I-2.1 defines the general eligibility of the population covered by the Family Support Program. N.J.A.C. 10:37I-3.1 describes the role of the family support coordinator. N.J.A.C. 10:37I-4.1 through 4.4 details the responsibilities and membership of the Regional and Statewide Family Support Working Groups required by P.L. 1995, c.314. N.J.A.C. 10:37I-5.1 defines the scope and purpose of the Intensive Family Support Services program. N.J.A.C. 10:37I-5.2 requires the development of policies and procedures to ensure that services provided comply with the rules of this chapter; support the concept and delivery of flexible and individualized educational and supportive activities; identify and prioritize the target population; require individual family assessment and goal setting; monitor and integrate with an overall quality assurance plan; assure that families provide input into all aspects of the program; assure program access regardless of ability to pay or cultural or linguistic differences; and monitor each family's wait for

service. N.J.A.C. 10:37I-5.3 defines the population intended to receive these services. N.J.A.C. 10:37I-5.4 clarifies who is to be considered an active participant in the program and N.J.A.C. 10:37I-5.5 defines the circumstances in which a family may be terminated from services. The package of services to be provided and a process for planning those services are detailed in N.J.A.C. 10:37I-5.6. Service coordination requirements are delineated in N.J.A.C. 10:37I-5.7. N.J.A.C. 10:37I-5.8 establishes the minimum requirements for assessing and documenting the family's level of concern, strengths and vulnerabilities, needs, functioning, service preferences and progress. N.J.A.C. 10:37I-5.9 establishes the staffing requirements for these programs. N.J.A.C. 10:37I-5.10 sets the minimum requirements for staff training and training documentation. N.J.A.C. 10:37I-5.11 identifies minimum sets of information that are required to be included in a quality assurance process.

The proposed amendments were developed by a workgroup consisting of service providers, family advocates, the Family Support Coordinator working under the direction of a Statewide family advocacy organization and Division staff. Following is a summary of these amendments.

Throughout the rules, the term "family burden scale" has been replaced with "family concerns survey" to reflect more current and less negative terminology (See N.J.A.C. 10:37I-5.2(a)4, 5.7(c)2i, 5.8(a)2i, and 5.8(c)3vi). Previously, N.J.A.C.10:37I contained two separate definitions sections – N.J.A.C. 10:37I-1.3 and 5.2. For ease of reference, N.J.A.C. 10:37I-5.2 has been deleted and its terms and definitions merged with N.J.A.C. 10:37I-1.3. A proposed

amendment to N.J.A.C. 10:37I-5.1(b) describes the purpose of Intensive Family Support Services (“IFSS”) as offering families services that are “accessible” (rather than “assertive”). This amendment more accurately states that the delivery of these services is oriented to the needs of the family receiving them (N.J.A.C. 10:37I-5.1(b)). At N.J.A.C. 10:37I-5.1(b)l, the first sentence has been amended to emphasize that IFSS enhance family functioning by providing family members with greater knowledge about mental illness, treatment options, the mental health system and skills useful in managing and reducing symptomatic behavior. Grammatical changes have been made to N.J.A.C. 10:37I-5.2 to streamline the text – that is, the phrase “The PA shall have written and implemented policies and procedures which” has been added to the beginning of the subsection, rather than being repeated throughout the paragraphs 5.2(a)1-10. At N.J.A.C. 10:37I-5.2(a)10, a requirement that IFSS providers develop and implement written policies and procedures regarding IFSS access to and use of family assistance funds was added to reflect an existing responsibility of IFSS providers.

Several clarifications were added to N.J.A.C. 10:37I-5.4, Admission criteria. Rather than automatically placing on inactive status a family who does not use IFSS for three months or longer, a PA must now contact the family to assess the need for continued services (N.J.A.C. 10:37I-5.4(a)2). This direct contact is preferable to an automatic cut-off of services and will enhance the potential effectiveness of IFSS to a larger pool of those in need of such services. If, however, the family responds to the three-month phone inquiry that no

services are needed at that time, the family is placed on the inactive list and encouraged to contact IFSS should they wish to use the service again (N.J.A.C. 10:37I-5.4(a)2i). Families on inactive status remain on the mailing list so that they are kept informed of program events (N.J.A.C. 10:37I-5.4(a)2iii).

At N.J.A.C. 10:37I-5.6(c)2, an amendment emphasizes that the addition of services offered by the IFSS in a particular area shall be based on family needs, as determined in consultation with local family groups and the provider agency (PA).

Several amendments affect the records-keeping responsibility of the PA. First, the frequency of the administration of an IFSS assessment instrument has been changed (N.J.A.C. 10:37I-5.8(c)2i). Rather than administering the family concerns survey at admission, every six months, and at termination, the PA is required to administer this assessment at admission, at six and twelve months, and annually thereafter for active families. The family concerns survey shall also be administered when a family is placed on inactive status. This change will promote more efficient and effective implementation of the IFSS program. Second, the PA is now required to indicate on the service preference form that the family received information regarding self-help and other support resources in the community (N.J.A.C. 10:37I-5.8(c)3iii). This requirement will ensure that such information is regularly made available to families. In addition, because the two documents are inter-related, the review and possible revision of service preference forms must minimally follow the same timetable as that for the administration of the family concerns survey (N.J.A.C. 10:37I-5.8(c)2i). A third

change is that the PA must document a family's well-being when the six-month follow-up contact is made after the family has been placed on inactive status (N.J.A.C. 10:37I-5.8(c)6). Finally, the termination summary shall include, where possible, the final Family Concerns Survey to give a more complete picture of the family's response to IFSS (N.J.A.C. 10:37I-5.8(c)9i(3)).

One requirement has been added to the staffing section. IFSS PAs are now required to consider employing staff knowledgeable and experienced with minority or underserved families in their geographic area (N.J.A.C. 10:37I-5.9(b)5).

Several requirements have been added to the quality assurance section (N.J.A.C. 10:37I-5.11). IFSS providers must now comply with the licensure requirement applicable to all community mental health programs (see N.J.A.C. 10:37-10, promulgated in July, 2002) (N.J.A.C. 10:37I-5.11(a)). IFSS PAs must also comply with the client complaint/agency ombuds procedure promulgated in N.J.A.C. 10:37-4.6 so that families may have any complaints about services reviewed and addressed (N.J.A.C. 10:37I-5.11(b)). The PA must collect information regarding a family's satisfaction with services annually and at a family's termination from the program or placement on inactive status. Such information will allow the PA to assure families are satisfied with services and to immediately address program weaknesses as they arise (N.J.A.C. 10:37I-5.11(c)1). In addition, the PA must annually review aggregated information on referral sources of family members to its IFSS program to assure services are

accessible to all families regardless of income and whether or not the ill family member is enrolled in the PA's services (N.J.A.C. 10:37I-5.11(e)).

Social Impact

The rules proposed for readoption with amendments will have a positive social impact on participants in intensive family support services by establishing, within applicable legal parameters, uniform policies and procedures regarding intensive family support services. Past practice has demonstrated that intensive family support services, while targeted to the needs of relatives and significant others whose lives are significantly impacted by the mental illness of a family member, also have a positive impact on the course of that person's mental illness. Research evaluations have shown intensive family support services to significantly reduce a family's level of concern in caring for a mentally ill relative, improve a family's satisfaction with mental health services and significantly reduce the need for psychiatric inpatient and crisis services.

The rules proposed for readoption will positively impact families eligible to receive services by establishing standards designed to promote the effective delivery of appropriately prioritized services. Additionally, the standards contained in the rules proposed for readoption with amendments assist provider agencies to attain their goal of providing high quality and responsive services. The Division benefits from the readoption of these standards because they provide an appropriate measure to use in determining whether service delivery meets basic minimum standards. Finally, the proposed amendments will provide

greater specificity and explanation of the rules' requirements and, thus, enhance the reader's understanding and advance notice of the rules' provisions.

Economic Impact

The funding of, and the establishment of standards for, the services which are the basis of these rules have a positive impact on families with limited incomes because they are made available to them at no cost. The Department believes that the provider agencies can comply with the rules proposed for readoption with amendments without expenditures in addition to the funding received from the Division or other sources in relation to these services. The rules proposed for readoption with amendments are not intended or expected to have an impact on the amount of Division funding available to agencies to provide these services in the future. The Department also believes that taxpayers throughout the State ultimately benefit from the effective delivery of these services, because the services reduce the need for expensive psychiatric hospital stays.

Federal Standards Statement

A Federal standards analysis is not required because the rules proposed for readoption with amendments are not subject to any Federal requirements or standards.

Jobs Impact

The rules proposed for readoption with amendments will neither generate nor cause the loss of any jobs.

Agriculture Impact

The rules proposed for readoption with amendments would have no impact on agriculture in the State of New Jersey.

Regulatory Flexibility Analysis

Some of the agencies licensed to provide Intensive Family Support Services may employ fewer than 100 employees full-time, and, thus, may qualify as small businesses, as that term is defined in the Regulatory Flexibility Act, N.J.S.A. 52:14B-16 et seq. The rules proposed for readoption with amendments impose some minor reporting, recordkeeping, and other compliance requirements upon such provider agencies. Specifically, N.J.A.C. 10:37I-5.2 requires written policies and procedures to assure flexible, accessible and individualized services; to define and prioritize the target population; to establish how services shall be designed, monitored and integrated into the agency's overall quality assurance plan; to assure the proper orientation of respite workers; and to regulate IFSS access to and use of family assistance funds. N.J.A.C. 10:37I-5.4 requires specific follow-up procedures when a family becomes inactive. N.J.A.C. 10:37I-5.6 establishes minimum content topics for psychoeducation services. N.J.A.C. 10:37I-5.7 requires the PA to develop an IFSS brochure that must be circulated in the community.

Several amendments affect the requirements for service assessment, planning, recordkeeping and progress notes (N.J.A.C. 10:37I-5.8). First, in addition to administering the Family Concerns Survey at admission, every six months, and at termination, the provider must now also administer this assessment at twelve months and annually thereafter for active families, and when a family is placed on inactive status (N.J.A.C. 10:37I-5.8(c)2.i). Second, the provider is required to indicate on the service preference form that the family received information regarding self-help and other support resources in the community (N.J.A.C. 10:37I-5.8(c)3.iii). Third, the provider must document a family's well-being when the six-month follow-up contact is made after the family has been placed on the inactive status (N.J.A.C. 10:37I-5.8(c)6). Finally, the termination survey shall include, where possible, the final Family Concerns Survey to give a more complete picture of the family's response to IFSS (N.J.A.C. 10:37I-5.8(c)9.i(3)).

N.J.A.C. 10:37I-5.9 establishes the staffing requirements for the program and N.J.A.C. 10:37I-5.10 requires the PA to develop an individualized training plan for each IFSS staff member and to document the training received by workers. This section also requires the PA to develop resources sufficient to provide accessible, appropriate education to families. N.J.A.C. 10:37I-12 requires specific quality assurance and utilization review activities, including compliance with client complaint/ombuds procedures, the collection of information regarding family satisfaction with services and their levels of concern, the review of aggregated information regarding referral sources of family

members to the IFSS program, and the incorporation of documented feedback into the quality assurance process.

The reporting, recordkeeping and other compliance requirements imposed upon provider agencies must be uniformly applied, regardless of the size of the provider agency, to ensure that families receiving these services throughout the State do so in accordance with basic minimum standards of quality. These standards are important because many mentally ill family members would be at risk of more restrictive and expensive hospitalizations, unless these services are competently and effectively provided. Additionally, these agencies are individually funded by the Division to be able to meet these requirements and it is not anticipated that compliance will require the employment of professional services by providers.

Smart Growth Impact

It is not anticipated that the rules proposed for readoption with amendments will have any impact on the achievement of smart growth and the implementation of the State Development and Redevelopment Plan.

Full text of the proposed readoption may be found in the New Jersey Administrative Code at N.J.A.C. 10:38A.

Full text of the proposed amendments follows (additions indicated in boldface thus; deletions indicated in brackets [thus]):

SUBCHAPTER 1. GENERAL PROVISIONS

10:37I-1.1 Purpose; authority

(a) Pursuant to P.L. 1995, c.314, the Division of Mental Health Services of the Department of Human Services shall establish a program of family support services designed to strengthen and promote families who provide care in the community for a family member with a serious mental illness.

(b) A Statewide family support policy for persons with a serious mental illness shall acknowledge that families themselves are able to define their own needs and select their own services; these family supports shall be chosen by families, controlled by families and monitored by families.

(c) The system of family support shall vary in scope and intensity based upon the needs of a particular family unit and shall include, but not be limited to, the following:

1. Service coordination;
2. Estate and transition planning;
3. Housing assistance;
4. Homemaker assistance;
5. Accessing vocational and employment services;
6. After-school care;
7. Transportation;
8. Respite care;
9. Family education and training;

- 10. Medication education;
- 11. Self-advocacy training;
- 12. Entitlement training; and
- 13. Other services as identified by the family.

(d) Adults with a serious mental illness should be afforded the opportunity to make decisions for themselves, live in typical homes and communities and exercise their full rights as citizens. When families serve as the primary provider of care for a family member with a serious mental illness, the families should be provided with the supports they need to sustain that family member with dignity in a community setting, within available funding limits.

(e) No more than 10 percent of funds disbursed to a PA shall be allocated for administrative purposes.

(f) The Division and any agency funded by the Division to provide family support services shall assist families in obtaining all other sources of funding before using funds appropriated pursuant to and available for the purposes of P.L. 1995, c.314.

(g) The services provided pursuant to this act shall not supplant any existing rights, entitlements or services for which the family or family member with a serious mental illness may be eligible.

(h) Notwithstanding the provisions of any law to the contrary, the family support services provided pursuant to P.L. 1995, c.314 shall be considered a State benefit and shall not be counted as income for the purposes of State taxation or eligibility for other State benefits.

10:37I-1.2 Scope

The provisions of this chapter shall apply to all families who reside in the State of New Jersey and who are actively involved in caring for, or supporting, a family member with a serious mental illness.

10:37I-1.3 Definitions

The following words and terms, when used in this chapter, have the following meanings, unless the context clearly indicates otherwise:

"Adult" means any individual 18 years of age or older and those who are transitioning into adult systems of care.

"Advocacy" means staff activities that, in cooperation with families, help the community and other professionals understand and respond to the needs of families with a mentally ill member (for example, technical assistance to other service providers or community organizations; supporting family members to participate and influence mental health policy formation, assertiveness training for family members on how to present themselves to professionals); or staff activities on behalf of a specific family (for example, meeting with employers to encourage flexible work schedules or emergency leaves).

"Commissioner" means the Commissioner of the Department of Human Services.

"Department" means the Department of Human Services.

"Division" means the Division of Mental Health Services in the Department of

Human Services.

"Engagement" means the process of establishing a collaborative relationship with a family built on caring and trust whereby the IFSS program establishes its value to the family by addressing its immediate needs, conveying a sense of hope and "being there" for the family in times of need.

"Family" means persons related to the family member with a serious mental illness by blood, marriage, adoption, guardianship, foster care or other significant care giving relationship.

"Family concern" means the objective and subjective experience of families coping with the acute and long-term responsibilities associated with community care and treatment. Family concerns may include disrupted family life, worry, stigma and sense of loss, as well as tangible costs in savings spent, time lost, and social isolation.

"Family concerns survey" means a valid and reliable instrument that measures objective and subjective pressures that a family experiences in caring for their mentally ill member.

"Family satisfaction with services" means a measurement of a family's experience with a particular PA as to the quality, impact, accessibility and relevance of IFSS.

"Family support group" means a time-limited or ongoing group in which families meet together to provide mutual support, information and opportunity to interact with other families having similar concerns and to help ease the isolation and stigmatization that many families feel.

"Family support services" means a coordinated system of on-going public and private support services which are designed to maintain and enhance the quality of life of a family.

"Family unit" means the family member with a serious mental illness and his or her family.

"Intensive family support services (IFSS)" means a range of family driven supportive activities designed to improve the overall functioning and quality of life of families with a mentally ill relative.

"Level of Family Concern" means the results achieved through administration of the Family Concerns Survey.

"NAMI New Jersey" is the name of a New Jersey Statewide self-help and advocacy organization dedicated to improving the lives of people with mental illnesses and their families.

"NAMI New Jersey Family to Family Education Program" means a family to family education program given by families of people with mental illness for families of people with mental illness.

"Program" means the program of family support services established pursuant to this chapter.

"Provider agency (PA)" means a public or private organization which has a contract with the Division to provide intensive family support services, and which meets the requirements contained in N.J.A.C. 10:37.

"Psychoeducation group" means a multi-family group which meets on a regularly scheduled, time-limited basis for the purpose of providing families with a greater

knowledge of mental illness, treatment options and skills useful in managing the illness within the family and supporting the recovery process.

"Referral/service linkage" means staff activities which provide individualized help or guidance to families in procuring needed mental health and non-mental health services or assistance (for example, applications for entitlements, referral to counseling, linkage with home health aide or visiting nurse associations).

"Respite" means non-emergency services designed to allow an individual family planned time away from their ill member living at home.

"Serious mental illness" means a diagnosable mental disorder which is sufficiently severe and enduring to cause periodic or lasting functional impairment in one or more life areas, often recurrent contact with the mental health system, or a significant risk of hospitalization in a State, county or private psychiatric institution.

"Single family consultation" means staff activities related to providing information to and consultation with an individual family on an "as needed" basis in order to enhance the overall functioning of the family with a mentally ill member.

"Statewide family advocacy organization" means an organization consisting primarily of family members of people with a serious mental illness that is dedicated to improving the lives of persons with serious mental illness and their families through mutual support, education and advocacy.

SUBCHAPTER 2. ELIGIBILITY CRITERIA

10:37I-2.1 General eligibility

(a) A family is eligible to participate in the program if the family resides in the State and is actively involved in caring for, or supporting, a family member with a serious mental illness.

(b) The services provided pursuant to this chapter shall not supplant any existing rights, entitlements or services for which the family or family member with a serious mental illness may be eligible.

SUBCHAPTER 3. FAMILY SUPPORT COORDINATOR

10:37I-3.1 Role of the coordinator

(a) The family support program shall be monitored by the Division and administered by a Family Support Coordinator working under the direction of a Statewide family advocacy organization designated by the Division to administer the program. The Statewide family advocacy organization shall not be under contract with the Division to provide Intensive Family Support Services.

(b) The Family Support Coordinator shall be qualified by training and experience to perform the duties of this position, pursuant to N.J.S.A. 30:4-177.47, as demonstrated by the following:

1. A master's level degree in social work, psychology, public health or other similar advanced degrees.
2. Five years experience in the planning, coordination and implementation of services for people with serious mental illness and their families.
3. Experience in the development of needs assessments.
4. Experience in the development of family support services.

5. Ability to facilitate workgroups consisting of family members.

(c) The Family Support Coordinator, in conjunction with the Statewide family advocacy organization and local family advocacy groups, shall work to expand and establish family support services throughout the State, in accordance with 1 through 3 below.

1. In conjunction with the three regional family working groups and the Statewide family working group, established pursuant to N.J.S.A. 30:4- 177.48, the Family Support Coordinator shall adopt, review and revise as needed, but no less than annually, a State Family Support Services Plan for Families of Persons with a Serious Mental Illness. The Plan shall identify:

- i. The needs, goals and family priorities for the provision of family support services;
 - ii. Strategies to provide outreach and coordinated delivery of support services;
- and
- iii. Identification of additional funding needs for the program to supplement funds appropriated pursuant to and available for the purposes of this chapter.

2. The Family Support Coordinator shall coordinate efforts by public and private agencies and local family advocacy groups. Coordination shall include, but not be limited to:

- i. The identification of services provided by different agencies to avoid duplication;
- ii. Planning with all agencies to ensure that gaps in services are filled; and
- iii. The coordination of activities for receiving and adopting input from local family

advocacy groups.

3. At least annually, the Family Support Coordinator shall report in writing to the Statewide family advocacy organization and the Division on the efforts of the regional family working groups to effectuate the purposes of P.L. 1995, c.314 (N.J.S.A. 30:4-177.43 et seq.).

SUBCHAPTER 4. FAMILY SUPPORT WORKING GROUPS

10:37I-4.1 Responsibilities of regional family support working groups

- (a) There shall be three regional working groups, corresponding to regions established by the Division.
- (b) The regional family working groups shall assess regional needs for family support services and make recommendations to the Statewide family working group.

10:37I-4.2 Membership of regional family support working groups

- (a) Members of the three regional working groups shall be designated by the Family Support Coordinator in conjunction with the Statewide family advocacy organization.
- (b) Members shall serve without compensation and shall include a family member of a person with a serious mental illness, a person with a serious mental illness or other representative of a group interested in advocating for persons with serious mental illness and their families.

10:37I-4.3 Responsibilities of Statewide family working group

The Statewide family working group shall monitor the support services from the three regions and provide recommendations to the coordinator regarding family support services.

SUBCHAPTER 5. INTENSIVE FAMILY SUPPORT SERVICES STANDARDS

10:37I-5.1 Scope and purpose

(a) The rules in this subchapter shall apply to all provider agencies (PAs) of intensive family support services funded by the Division.

(b) The purpose of intensive family support services (IFSS) is to improve the overall functioning and quality of life of families with a mentally ill relative. Family members and professionals work collaboratively to provide each family with the knowledge, skills and supports which they identify as useful to a family's overall functioning and sense of control. This purpose shall be achieved through reaching out to relatives and others closely involved in and concerned about their ill family member's daily functioning and offering them a choice of supportive activities which are family driven, [assertive] accessible, and flexible in frequency, location and hours of delivery.

1. IFSS enhance family functioning [through] by providing the family with a greater knowledge [of] about mental illness, treatment options, the mental health system and skills useful in managing and reducing symptomatic behaviors of the ill family member due to the illness. Families also learn patterns of communication and levels of environmental stimulation which have been

demonstrated to reduce the number of psychiatric crises and hospitalizations. Families are encouraged to attend to their own needs for time off and social activities and are provided the supports to make it possible. Education and support activities may include psychoeducation groups, single family consultations, respite, family support groups, systems advocacy, referral/service linkage, and medication education. Services shall be delivered in the family home, at the agency or at other sites in the community convenient to individual family members. Families choose from an array of services those that are most relevant to their circumstances which may change over time.

(c) The rules in this subchapter provide a description of the clients for whom the services are targeted, services to be provided, the requirements and responsibilities of the PAs and their staff, and the procedures required to provide the service.

[10:371-5.2 Definitions

The words and terms in this subchapter shall have the following meanings, unless the context clearly indicates otherwise:

"Advocacy" means staff activities that, in cooperation with families, help the community and other professionals understand and respond to the needs of families with a mentally ill member (for example, technical assistance to other service providers or community organizations; supporting family members to participate and influence mental health policy formation, assertiveness training for family members on how to present themselves to professionals); or staff

activities on behalf of a specific family (for example, meeting with employers to encourage flexible work schedules or emergency leaves).

"Engagement" means the process of establishing a collaborative relationship with a family built on caring and trust whereby the IFSS program establishes its value to the family by addressing its immediate needs, conveying a sense of hope and "being there" for the family in times of need.

"Family burden" means the objective and subjective experience of families coping with the acute and long-term responsibilities associated with community care and treatment. Burden is experienced as disrupted family life, worry, stigma and sense of loss, as well as tangible costs in savings spent, time lost, and social isolation.

"Family burden scale" means a ranking of family burden.

"Family support group" means a time-limited or ongoing group in which families meet together to provide mutual support, information and opportunity to interact with other families having similar concerns to help ease the isolation and stigmatization that many families feel.

"Intensive family support services (IFSS)" means a range of family driven supportive activities designed to improve the overall functioning and quality of life of families with a mentally ill relative.

"NAMI New Jersey" is the name of a New Jersey Statewide self-help and advocacy organization dedicated to improving the lives of people with mental illnesses and their families.

"NAMI New Jersey Family to Family Education Program" means a family to family education program given by families of people with mental illness for families of people with mental illness.

"Provider agency (PA)" means a public or private organization which has a contract with the Division to provide intensive family support services, and which meets the requirements contained in N.J.A.C. 10:37.

"Psychoeducation [groups] group" means a multi-family group which meets on a regularly scheduled, time-limited basis for the purpose of providing families with a greater knowledge of mental illness, treatment options and skills useful in managing the illness within the family and supporting the recovery process.

"Referral/service linkage" means staff activities which provide individualized help or guidance to families in procuring needed mental health and non-mental health services or assistance (for example, applications for entitlements, referral to counseling, linkage with home health aide or visiting nurse associations).

"Respite" means non-emergency services designed to allow an individual family planned time away from their ill member living at home.

"Single family consultation" means staff activities related to providing information to and consultation with an individual family on an "as needed" basis in order to enhance the overall functioning of the family with a mentally ill member.]

10:37I-5.[3]2 Written policies and procedures

(a) The PA shall develop and implement written policies and procedures to ensure that the services provided comply with the rules in this chapter. The PA shall have written and implemented policies and procedures which

1. [The PA shall have written and implemented policies and procedures which] support the concept and delivery of flexible and individualized educational and supportive activities designed to improve the overall functioning and quality of life of families with a mentally ill relative[.];

2. [The PA shall have written and implemented policies and procedures to] define and prioritize the target population for IFSS and the PA's methods to identify potential families and offer them services[.];

3. [The PA shall have written and implemented policies and procedures] [requiring] require individual family assessment and goal setting. Assessments shall include, but not be limited to, the administration of a [family burden scale] Family Concerns Survey approved by the Division, after submission and review of scientific testing documentation. Such assessment shall be used to plan IFSS with family members[.];

4. [The PA shall have written and implemented policies and procedures] [describing] describe how IFSS are monitored and how these monitoring activities are integrated with an overall quality assurance plan. Policies and procedures shall incorporate regular family feedback as to the quality, impact, accessibility, and relevance of IFSS. Policies and procedures also shall include how the administration of Division approved instruments to measure family satisfaction with services and level of family concern [burden] shall occur, who

shall administer them, and how findings will be incorporated into their overall quality assurance plan[.];

5. [The PA shall have written policies and procedures to] assure that there is family input into all aspects of the program[.];

6. [The PA shall have written policies and procedures to] assure that all families shall have access to the full range of IFSS regardless of ability to pay and that any fees imposed by the PA will not serve as a barrier to engaging families into services[.];

7. [The PA shall have written policies and procedures to] assure that respite workers are oriented to individual families and their ill family member. Orientation shall include specific information about the family and a meeting with the ill family member prior to respite activities[.];

8. [The PA shall have written policies and procedures to] assure that services are culturally and linguistically accessible to all eligible families[.];

9. [The PA shall have written policies and procedures to] monitor each family's wait for service and the prioritization of families for service[.];

10. relate to IFSS access to and use of family assistance funds.

10:37I-5.[4]3 Population priorities

(a) Services shall be offered to parents, spouses, siblings and children of [people] adults with a serious mental illness. Others who may use such services include relatives who are closely involved in and concerned about the ill family

member's daily functioning, or non-relatives who are the ill member's primary caregivers.

1. For the purposes of the IFSS program priorities, serious mental illness shall be defined, using the Diagnostic and Statistical Manual of Mental Disorders (IV) of the American Psychiatric Association, as amended and supplemented, incorporated herein by reference. Serious mental illness is a primary psychiatric diagnosis on Axis I or exhibiting symptoms of:

- i. Schizophrenia or other psychotic disorders;
- ii. Major depressive disorders;
- iii. Bipolar disorders;
- iv. Delusional disorders;
- v. Schizoaffective disorder; or
- vi. Obsessive-compulsive disorder in the severe range.

2. Family members of close relatives with personality disorders in the severe range may qualify if their ill family member has a history of or is at risk of hospitalization as a result of the personality disorder.

(b) Services shall be made available to family members living in the geographic area served by the PA regardless of the family's ability to pay for services or whether or not their ill family member is enrolled in agency services.

(c) Efforts shall be made to offer services to families in crisis. Referral protocols shall be developed with psychiatric inpatient and screening center programs which recognize the need of families at such times for support.

10:37I-5.[5]4 Admission criteria

(a) A family shall be considered an active participant in IFSS once an initial face-to-face assessment of the family's needs has occurred and further services are requested.

1. A family shall be considered part of the PA's active caseload after the initial intake, face to face assessment, description of service options and the family agrees to further service.

i. In the event that a family chooses not to meet for a face-to-face assessment but wishes to receive services, this fact shall be documented in the record and the case shall be opened.

2. If a family does not use IFSS for a period of three months, [or longer, they shall be placed on inactive status and not considered part of the PA's active caseload] the PA shall contact the family to assess the need for continued services.

i. [Families] If no services are needed at that time, the family shall be [contacted after three months to be encouraged] placed on inactive status and encouraged to contact [the] IFSS at any time if they want to again use any of the program's services.

ii. The PA shall contact a family [members] placed on inactive status [a minimum of once every] six months later to monitor how they are doing and again offer assistance[, if the family agrees].

iii. Families on inactive status will remain on the program's mailing list and continue to receive announcements unless they indicate otherwise.

3. A family may return to active status at any time in the future so long as it continues to qualify for service.

(b) A family shall remain active as long as it requests the assistance of IFSS.

(c) Criteria shall be developed to establish immediacy of need and priority for service.

10:37I-5.[6]5 Criteria for termination of services

(a) Termination from IFSS shall take place when one of the following occurs:

1. The family states they no longer want services; or
2. The family moves out of the geographic area served by the PA and the PA's services are no longer accessible to the family. If the family moves to another county with an IFSS program, the PA shall inform the family and provide a contact name and telephone number.

10:37I-5.[7]6 Service planning and services to be provided

(a) IFSS PAs shall include single family consultations in the service package they offer to families.

1. Single family consultations shall be scheduled in the family home or other sites and at times convenient to the family.
2. Single family consultations shall include, but not be limited to, individualized strategies for coping, problem solving, support, education, direct assistance, referral and linkage and advocacy.

3. IFSS staff shall provide information to family members according to their individual needs. IFSS staff shall not disclose any information disclosed to a doctor, psychologist, social worker or therapist in the context of a therapeutic relationship, with the limited exceptions defined in N.J.S.A. 30:4-24.3, regarding a mentally ill family member without that member's written consent. IFSS staff shall assist the family in obtaining such written consent while respecting the ill family member's right to withhold such consent.

4. IFSS PAs shall have mechanisms in place to respond to a family in crisis during off-hours including evenings and weekends.

(b) IFSS PAs shall include psychoeducational groups in the service package they offer to families.

1. Psychoeducation groups shall at a minimum include the following:

- i. Support for the family including exploration of feelings and attitudes about the illness and its impact on the loved one;
- ii. Clear presentations about the biological causes of specific mental disorders, as well as facts about how the illness is likely to affect the ill family member's thinking, feelings and behaviors;
- iii. Review of symptoms of mental illness, including positive and negative ones, along with discussions of methods of symptom management;
- iv. Explanations of the role of medication in the management of mental illness, including discussions of the major drug classes and their therapeutic and side effects;
- v. Reduction of relapse and rehospitalization by enlisting families in early

identification of prodromal symptoms;

vi. Training in coping and stress reduction strategies, minimally including limit setting, problem solving and communication techniques;

vii. Adjustment of family expectations concerning the patient's social functioning and introduction of the idea of incremental progress and recovery, rather than cure;

viii. Education about the role of the mental health system and strategies to promote continuity of care;

ix. Attempts to increase family social support networks in order to reduce isolation;

x. Information about other available resources, such as residential and substance abuse programs and self-help groups; and

xi. Strategies for future planning, such as estate management and guardianship, and vocational options.

2. Groups shall be geographically, linguistically and culturally accessible to eligible families.

3. Groups shall be scheduled at times convenient for family participation.

4. The NAMI-NJ Family to Family Education Program shall be made an option for families receiving IFSS. The schedule of IFSS psychoeducation series and NAMI New Jersey's Family to Family Education program shall be coordinated, where both services are available.

(c) Additional services shall be offered to families based on local and individual family needs as determined by families in consultation with the PA. Consultation

with local family groups on the menu of services offered shall occur annually.

1. The PA shall identify existing resources or develop new ones in response to family requests for assistance which may change over time.

2. If needed, [Additional] additional services may include, but not be limited to, the following:

- i. Respite services which may be provided in the home, out of the home and as a day, evening or overnight service;
- ii. Family support groups including specialized groups targeted to parents, children, spouses;
- iii. Advocacy; and
- iv. Referral/linkage.

10:37I-5.[8]7 Service coordination

(a) The PA shall coordinate services with other mental health family support organizations and programs. Evidence of service coordination shall be reflected in the clinical record.

(b) In order to identify the target population, IFSS staff shall develop collaborative relationships with the social work staff at State and county psychiatric hospitals, screening centers, designated short term care facilities, and local inpatient units and jails in order to reach out to families from their service area who are experiencing a crisis with their ill family member.

1. The PA shall develop an IFSS brochure that shall be circulated widely in the

community (for example, in visiting rooms/bulletin boards of local hospitals; offices of private practitioners and clergy; community bulletin boards in local libraries, supermarkets, and newspapers).

2. IFSS staff shall educate psychiatric inpatient and screening center staff on the needs of families in crisis and establish referral protocols.

10:37I-5.[9]8 Assessment, service preferences and record documentation

(a) The PA shall maintain individualized and complete records for all families for whom an assessment is completed and service preferences are documented and cosigned by the family.

(b) The records shall be maintained in an up-to-date, organized manner in a secure location at the PA.

(c) The records shall contain all relevant information and shall be maintained to preserve confidentiality. At a minimum, the records shall contain the following:

1. The original IFSS family intake information which identifies at a minimum:

i. The names of involved family members;

ii. Referral source;

iii. Presenting needs; and

iv. Whether or not the family is dealing with an emergent crisis.

2. IFSS assessments including:

i. A [family level of burden Scale] family concerns survey approved by the Division, after submission of documentation, [to the Division which shall be] The records shall include all family concern surveys administered by IFSS staff at

admission into the program [and] at [every] six months, 12 months, [thereafter]
and [at termination] and annually thereafter. Level of concern information shall
also be collected when families are placed on inactive status;

ii. Family strengths and vulnerabilities: for example, their understanding of their loved one's illness and treatment options, aging and health issues, social support network;

iii. Expressed needs;

iv. Ill family member's functioning, diagnosis and medications, if known;

v. Service preferences including location of services; and

vi. The assessment process shall continue throughout the entire length of service. New information pertaining to the assessment shall be documented in the record as it occurs;

3. IFSS service preferences, as follows:

i. The record shall contain documentation of a family's service preferences which shall be cosigned by the family support specialist and the family members participating in the Intensive Family Support Program;

ii. The record shall contain documentation that the range of family support services available in the county has been explained to the family;

iii. The PA shall request family members to indicate in writing on the service preference form that they have received information regarding self-help and other support resources in the community;

[iii]iv. Documentation of service preferences shall be completed as part of the assessment process;

[iv]v. Service preferences shall be related to documented family need and request for services; and

[v]vi. Service preferences shall be reviewed with the family and revised whenever there is a significant change in the family's situation but minimally [every six months] in conjunction with the administration of the [family burden] Family Concerns Survey, as delineated herein at (c)2i above;

4. Progress notes, as follows:

- i. A summary of services shall be documented for each face-to-face contact;
- ii. The initial face-to-face contact with the family shall be documented specifying the outcome of the contact and other significant information available at the time;
- iii. Progress notes shall make reference to the family's preferences and reflect the family's status, interventions provided, family response to interventions and change in service provision;
- iv. Progress notes shall reflect collateral contacts and communication with persons other than the family on behalf of the family which impact on the family's status or service provision;
- v. Progress notes shall reflect status of the family's natural support system;
- vi. Progress notes shall specify location of face-to-face contact; and
- vii. Notes shall be properly authenticated with a signature, date and title for each entry;

5. Activity logs which identify the type, date and frequency of all support services a family is receiving including those provided by IFSS PAs and other agencies, and self-help organizations, when known;

6. Documentation which summarizes the family's [status] well-being when placed on inactive status and at the six-month follow-up contact required by N.J.A.C. 10:37I-5.4(a)2ii;

7. Relevant release of information forms;

8. Documentation that the family has received a referral to their local NAMI- NJ affiliate and other self-help organizations; and

9. PA termination from IFSS program summary.

i. The summary shall include:

(1) The reasons for termination;

(2) Family's status at termination;

(3) Family response to services including, where possible, a family's self-assessment of progress and further needs, and a final family concerns survey;

and

(4) Recommendations, plans or linkages for further service, if needed.

10:37I-5.[10]9 Staffing requirements

(a) The PA shall employ staff with demonstrated attitudinal qualities, skills and competencies in knowledge areas such as:

1. Ability to provide up-to-date information about bioneurological aspects of major mental illnesses and the medications used to treat these illnesses;

2. Ability to provide information on the impact of substance use and abuse on the course of mental illnesses; risks associated with mixing various psychotropic

medications with other mood altering substances and knowledge of Al-Anon resources geographically accessible to the family when needed;

3. Knowledge of diathesis-stress research on communication patterns and environmental stimulation as it relates to relapse rates and symptomology;

4. Knowledge of mental health and social resources in the county and the ability to draw upon local expertise as needed;

5. Knowledge of principles of adult education and group process;

6. A genuine regard for families of persons with mental illnesses, who have not caused their relative's illness, who have valuable insights and who can have a strong positive influence on their ill member's recovery;

7. Able to design and deliver workshops and presentations;

8. Responsive to the feelings and concerns of family members;

9. Ability to reach out to minority families and serve them effectively;

10. Ability to teach families new skills and coach them in using their skills in multiple environments as circumstances require;

11. Ability to provide assertiveness training to family members on how to present themselves to professionals in the mental health system;

12. Experienced and comfortable with providing services in the family home and other off-site service provision;

13. Flexible with regard to time and place in order to accommodate the individual needs and preferences of family members;

14. Ability to establish a referral network and to provide technical assistance to

professionals within the mental health system and other community groups regarding the value of seeing the ill family member as part of a family unit deserving attention and support (for example, religious groups; health care providers); and

15. An understanding of how to provide respite in a family home and to train respite workers as necessary;

(b) Each PA shall employ sufficient numbers of qualified staff. Staff shall have skills which will enable them to educate families and collaborate with them in the rehabilitation process, support them in coping with their relative's illness and enhance their effectiveness as caregivers. IFSS staff shall help families maintain an environment that is conducive to the recovery process and to enjoy a better quality of life during the course of the illness.

1. The PA shall hire at least one full time employee who shall function as a Family Support Specialist and not be shared with other PA program elements.

2. Each Family Support Specialist shall have an earned Master's degree in a mental health clinical discipline and possess a minimum of three years experience providing mental health services to people with severe and persistent mental illness and their families.

i. If the PA employs additional voluntary or paid family support staff as part of its IFSS program, then the Family Support Specialist shall have supervisory experience.

3. Additional family support staff and consultants employed by the PA in its IFSS

program shall at a minimum have a Bachelor's level degree in the behavioral health sciences and two years experience working in the mental health field or a registered nursing degree and two years experience working in the mental health field.

i. Bachelor's degree level staff shall be supervised by the Master's degree level Family Support Specialist.

4. IFSS PAs shall consider employing knowledgeable people with first hand experience in living with a loved one with severe mental illness on a paid or volunteer basis. A Bachelor's level degree may be waived for knowledgeable and experienced family members.

5. IFSS PAs shall also consider employing people with knowledge and experience regarding minority or underserved families in the geographic area.

[5]6. IFSS PAs shall involve families in the staff selection process.

(c) Respite workers employed by the PA must at a minimum have a high school diploma and be specifically trained to provide respite services.

10:37I-5.[11]10 Training

(a) The PA shall develop and implement an individualized training plan for each IFSS staff member.

(b) Training plans and documentation of training received shall be made a part of the personnel file of each IFSS staff member.

(c) The PA shall provide IFSS staff the time and resources it needs to remain up-to-date with the latest published research on the etiology and treatment of brain disorders.

(d) The PA shall document specific training to respite workers. Training shall include, but not be limited to, the following topics:

1. Crisis/emergency response;
2. Medications and medication observation;
3. Overview of serious mental illness;
4. Mission of IFSS;
5. Basic etiquette for being in a family home;
6. Confidentiality requirements;
7. Orientation to local mental health services and community resources; and
8. Professional conduct.

(e) The PA shall provide staff the training resources it needs to provide education to families including, but not limited to, videotapes, workbooks, and informational brochures.

1. The PA shall provide sufficient resources to assure that information developed for families is linguistically accessible and culturally responsive.

10:37I-5.[12]11 Quality assurance

(a) The PA shall comply with the quality assurance and licensure requirements as promulgated in N.J.A.C. 10:37-9 and 10.

(b) The PA shall comply with the client complaint/agency ombuds procedure as promulgated in N.J.A.C. 10:37-4.6.

~~[(b)]~~(c) The PA shall collect information on family satisfaction with services.

1. Information on satisfaction with services shall be collected annually and at a family's termination from program or placement on inactive status.
2. The PA shall use a Division approved instrument.
3. The PA shall assure that findings from satisfaction with services surveys remain confidential and separate from the family's treatment record.

~~[(c)]~~(d) The PA shall collect information on each family's level of [burden] concern.

1. Level of [burden] concern information shall be obtained at intake, at six months, twelve [month] months, [intervals] and [at termination from program] annually thereafter. Level of concern information shall also be collected when families are placed on inactive status.

2. The PA shall use a Division approved instrument.
3. The PA shall review increases and decreases in family level of [burden] concern as part of its quality assurance process.

~~[(d)]~~(e) The PA shall make aggregated reports on family satisfaction, level of [burden] concern and types of services provided available to the Division upon request but no more than quarterly.

(f) The PA shall annually review aggregated information on referral sources of family members to its IFSS program.

~~[(e)]~~(g) The PA shall meet at least annually with members of local NAMI affiliates and other family support and self-help organizations, where available, to obtain feedback on how well activities of the PA and their organizations are coordinated. Feedback shall be made a part of the quality assurance process.

1. There shall be documented evidence that the feedback has been incorporated into the Quality Assurance Plan.

~~[(f)]~~(h) The PA shall also monitor and evaluate utilization of IFSS resources.

1. At a minimum, the following data shall be routinely collected and analyzed:

- i. The number of people who attend individual psychoeducational sessions or educational workshops;
- ii. The number of families who request and receive respite services and the amount of time spent providing respite services;
- iii. Wait for service data, including:
 - (1) The length of time from referral to intake interview;
 - (2) The length of time from intake interview to initiation of services; and
 - (3) Monthly number of clients on the waiting list, if applicable;
- iv. Caseload size, which is the number of families, per family support staff member; and
- v. The total number of face-to-face visits including the number of off-site face-to-face visits and the number of agency based face-to-face visits.